ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

MARCH 1989

MCC OF BOSTON
LIVING WITH AIDS: PRINCIPLES, POLICY, & PLAN FOR MINISTRY

This is a draft statement for consideration by the Board, Staff, and Congregation of MCC Boston. We hope that this effort may provide a helpful model for other churches. This draft will be discussed at a forum prior to the Spring congregational meeting, in the hopes that we as a congregation can affirm such a statement.

> Using the most conservative estimates...inadequate response to this burgeoning epidemic has set the stage for a major disaster. Even if everyone practiced safer sex and stopped sharing needles yesterday, by the end of 1995 almost half a million Americans will have full-blown AIDS.
>
> - Toward a Coherent National AIDS Policy
> Kenneth H. Mayer, M.D., Medical Director
> Fenway Community Health Center, Boston

The AIDS epidemic presents a social, political, ethical, and religious crisis as well as a medical one. We recognize that AIDS is a socially constructed epidemic, perpetuated by years of government neglect, and the systemic social forces of homophobia, racism, fear of sexuality, and structural inequities as to access to health care. We recognize that this epidemic has a unique impact on particular communities and populations, especially gay men, IV drug users, and third world people in North America and globally.

As a church, we are called to celebrate God's love, serve our community, and build for the future. Particularly as a church serving the lesbian and gay community, MCC is called to respond to the challenge of this epidemic with courage and foresight, to be of service and to witness to God's presence within us and among us in this crisis.

AIDS presents a challenge of leadership, particularly within the lesbian and gay community, and within the religious community. In the hope that MCC will provide this needed leadership, we as a community of faith affirm these principles as a basis for policy and plans for ministry.

We acknowledge that in this crisis, there is no "us and them" when it comes to AIDS. We as a community have AIDS and stand together as people living with AIDS.

We honor those among us currently living with AIDS as friends, families, lovers, colleagues, and co-teachers. We commit ourselves to remember with love those who have died, trusting scripture's promise that love never ends.

We recognize the denial that surrounds this epidemic, even within the lesbian and gay community and within our denomination. We choose to face our fears and move through them to a place of understanding and action. We ask that our church refuse to be re-focused on other issues as a way of avoiding dealing with AIDS.

This is intended as a living document, open to input and change as circumstances and needs change. It is open to dialogue, particularly with and among different people and communities uniquely affected by AIDS.

It is important to understand issues raised by this epidemic. It is important to articulate perspective, policies, and plans for ministry. It is important to take a stand, one that is faithful, gay-positive, and sex-positive. It is important that any statement such as this reflect a genuine environment of openness and care, of solidarity and mutual ministry with people at different stages of the HIV journey and the journey of AIDS. It is important to begin.

Toward these ends, we commit ourselves to the following:

1) Statement on non-discrimination for HIV status in all areas of church life - employment, leadership and participation.

2) Commitment to pursue health insurance and disability for employed staff.

3) Commitment to ministry to meet people needs: opportunities to care and support, including peer support for people at different stages of HIV; care for the sick; hospital and home visitation; death and dying; celebration of life cycles and transitions; bereavement.

4) Commitment to education: for ourselves: staff, leadership and congregation, with opportunities for in-service training. For our community: information available at church and in the newsletter, condoms, safer sex, HIV testing, women and AIDS, resources in the community.

5) Commitment to a wider perspective on this health crisis: recognizing disproportionate impact on minorities; growing impact on women and children; world-wide nature of this health crisis; ministries and perspective that includes other life-threatening illnesses.

6) Commitment to political action: to advocate for care, research and treatment; full civil rights for all HIV affected people; confidentiality of HIV testing; access to medical drugs and protocols.

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LIVING WITH AIDS: (Cont'd)

7) Commitment to work with our community, collaborating with AIDS organizations and religious groups, avoiding unnecessary duplication and seeking to identify what we as MCC can uniquely provide; encourage and supporting those members of our church who work with AIDS organizations (such as the Quilt, ACT-UP, or as buddies).

8) Commitment to continuing prayer and spiritual reflection and action, considering together pastoral and theological issues and needs raised by this crisis.

9) We call upon our denomination to creatively and responsibly address this crisis by:

- continuing in prayer and spiritual reflection;
- continuing in ministry and service within communities;
- articulating a statement of non-discrimination;
- developing structural responses to needs raised by this epidemic: health care and disability for employees, including pastors, funding for staff and programs for AIDS ministry, protocols for situations of pastoral leadership with AIDS providing assistance during the stages of HIV;
- continuing education within our denomination: ALERT, the UFMCC monthly news digest on AIDS;
- continuing education for clergy: opportunities for education at District and General Conferences;
- preparation of student clergy: demonstrated AIDS awareness, e.g. workshop experience or training by local AIDS organizations;
- working in partnership with people in our denomination who journey with HIV: opportunities for peer support and dialogue; access to communication and decision-making;
- pioneer in demonstrating leadership in the midst of this crisis -- within our denomination, the lesbian and gay community, the religious community, and in society;

(Editor's Note: On March 2, 1989, the UFMCC General Council was led in a four-hour workshop on "Managing Catastrophic Illness in the Workplace" by Dr. Alan R. Emery, psychologist, management consultant, and founding associate of the Center for Public Problem Solving. Dr. Emery is co-author of the book, Managing AIDS in the Workplace.

[ENCLOSED FOR YOUR CONVENIENCE IS AN OFFERING ENVELOPE FOR THE UFMCC AIDS MINISTRY. THANK YOU FOR YOUR SUPPORT]

NEW TREATMENTS TO WATCH, 1989

(by John S. James)

(Reprinted with permission from: AIDS Treatment News; Issue 72; Jan 1989)

Here are the potential AIDS therapies which we believe are most likely to become important in 1989.

This particular list only includes treatments for AIDS/HIV itself; therefore it omits other important new developments; for example, better antibiotics for opportunistic infections or treatments for anemia. All the AIDS therapies we selected as most promising turned out to be antivirals - although we did not start out with that criterion.

We included only "new" treatments, meaning ones which were seldom or never available before, but might become accessible for the first time in 1989. Therefore we did not consider existing treatments such as AZT or dextran sulfate.

We based this selection mainly on "quality rumors", choosing those treatments which are generating enthusiasm among medical professionals familiar with them. A few were too new to have rumors; we included them because of the reputations of those involved in their development.

The best source for additional information about most of these treatments is the new AIDS/HIV Experimental Treatment Directory (December 1988, Volume 2 Number 3), published by the American Foundation for AIDS Research (AmFAR). The directory can be obtained from AmFAR, 1515 Broadway, Suite 3601, New York, NY 10036-8901, (212) 719-0033.

* ddI (dideoxyinosine). ddI is a nucleoside analog (a drug in the same class as AZT), but appears much less toxic.

The first human trial, with 15 early AIDS/ARC patients who have now taken the drug for at least 14 weeks, started last summer at the U.S. National Cancer Institute. Another phase I (dosage and toxicity) trial is taking place at the New York University Medical Center in New York City, and the University of Rochester Medical Center, in Rochester, NY; a separate phase I trial is taking place in Boston. No human results have been published, although there are reports of patient improvements. More importantly from our perspective we have repeatedly heard rumors that the researchers working with ddI are very enthusiastic about it.

These rumors were indirectly supported by a dispute between top officials of the U.S. National Cancer Institute (NCI) and the Food and Drug Administration (FDA). Dr. Samuel Broder, recently appointed head of the NCI, and Dr. Bruce Chabner, director of the cancer treatment division at NCI, strongly criticized the FDA for not allowing NCI to begin tests of ddI in children under two with AIDS, before adult

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trials were finished. Dr. Broder himself had run the early NCI trial, the first human use of ddI; he must know as much as anyone about how to use the drug. He would hardly have made an issue of the FDA's refusal to allow immediate testing in children if problems had been encountered.

The new AmFAR directory (December 1988; see reference above) reports that ddI is believed to be ten times less toxic than AZT. "No substantial toxicity or bone marrow suppression have been noted in the NCI study; some patients have complained of mild headaches and lightheadedness. Because ddI is acid unstable, ingestion of an antacid is required prior to oral administration." The phase I clinical trial excludes persons with a history of heart disease or seizure disorder.

ddI appears to be effective in macrophages, and to be able to cross the blood-brain barrier to some extent.

What will happen next? At this writing, the phase I trial in New York City and Rochester has only recruited 9 or 42 subjects. The problem is not lack of interest by patients; New York University at least has a long waiting list. The bottleneck is in the study design. Each dosage level, starting with the lowest, must be tested for several weeks before the next higher dose can be tried (in different patients); this process must continue until the maximum tolerated dose is reached. It is also rumored that limited hospital space has caused delay (each patient is hospitalized for the first two weeks of treatment, as is commonly done in phase I studies). It is possible that Bristol Meyers which has rights to the drug, will begin a phase II trial without waiting to complete phase I, providing the FDA does not object.

ddI is easy to manufacture. If it is bogged down in red tape and institutional inertia, an underground will be inevitable.

For more information, see the latest AmFAR directory and the information cited there. For the best published report on the dispute between the NIH and the FDA, see the Chicago Tribune, Jan 5, 1989, page 4.

* Passive immunotherapy. This treatment consists of transfusions of plasma from healthy HIV-positive donors, selected to have high levels of effective anti-HIV antibodies, to recipients who lack those antibodies because they have reached a stage in the disease where they can no longer produce them. The plasma infusions, commonly given about once a month, can be dramatically helpful even to some persons with advanced AIDS. Only about 20 people have received this treatment so far, but there is great interest among both professionals and patients.

AIDS TREATMENT NEWS has already covered passive immunotherapy, so we will not repeat the details here. For more information, see issue #67, Oct 21, 1988, and issue #70, Dec 1, 1988. You can also call the Passive Immunotherapy Project a patient support group organized to obtain access to this therapy, at (415) 549-9137.

At this time the two major concerns about passive immunotherapy are (1) that FDA restrictions may delay access for as long as a year or more, and (2) that some physicians may offer the treatment but not do it properly, endangering their patients.

These concerns may seem to be opposites, but in fact they are two sides of the same problem. For the FDA could seriously hamper the organized, professional effort to do passive immunotherapy right - driving this treatment into the separate practices of individual physicians, where the FDA does not have jurisdiction. Excessive restriction could stymie the high quality, organized efforts, pushing the treatment into settings where there is less quality control.

ANTIVIRAL HERBS AND EXTRACTS: This category consists of traditional medicinal herbs which have shown antiviral activity in laboratory tests. We listed the following three:

* Hypericin. This chemical, found in the St. John's Wort plant, appeared to be an excellent anti-retroviral when tested in animals (against retroviruses other than HIV). It also shows anti-HIV activity in the laboratory. (Since few animals can be infected with HIV, the obvious animal test against HIV infection could not be done.) For background information on hypericin, see AIDS TREATMENT NEWS, issue #63, Aug 26, 1988, and issue #64, Sept 9, 1988.

So far we have received only one report of human use for AIDS/HIV, from a physician who has five patients who are using "Hyperforat", (a high-strength, standardized St. John's Wort extract available in Germany), with good to excellent results. It is generally believed that most of the St. John's Wort preparations available in the U.S. in health food stores are worthless, because they do not contain enough hypericin, the active ingredient. Laboratory testing is now going on to see if any of the U.S. preparations appear likely to be useful.

* Compound Q. This experimental treatment (also called GLQ 223, and not to be confused with coenzyme Q), is a protein derived from Chinese herbs. It worked very well in stopping HIV in laboratory tests, but no human trials have yet been done. Apparently the drug must be given intra- venously, so human experience with the herbs does not prove safety; toxicity tests are now being done in animals. The developer has applied to the FDA for permission to begin human testing.

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NEW TREATMENTS TO WATCH, 1989 (Cont'd)

Compound Q was developed by Genelabs in Redwood City, CA, with consultants from the University of California San Francisco, and the Chinese University of Hong Kong. The project is funded by the Swiss pharmaceutical company Sandoz Ltd., which will have exclusive rights to the product. Genelabs has previously worked with Stanford University in screening chemicals for possible use in AIDS treatment.

For more information about compound Q, see the AmFAR directory. Or see the article on new patients in The New York Times, Jan 7, 1989, or U.S. patent number 4,795,739, which was issued to the researchers early this month.

* Chinese anti-infection herbs. A screening program conducted by researchers at the Chinese University of Hong Kong and the University of California at Davis tested 27 herbs and found that 11 of them showed anti-HIV activity; five of these almost completely stopped the virus in the test tube. For more information, see AIDS Treatment News issue #61, July 29, 1988, and issue #68, November 4, 1988.

We do not have any new results at this time. Anocdotal results seem good.

* FLT (fluorodeoxythymidine). In recent Swedish tests, FLT was found several times as effective as AZT both against HIV in laboratory cultures, and against SIV, a related retrovirus, in monkeys. The drug has previously been tried in humans, as it was tested and rejected as a cancer therapy 20 years ago in East Germany.

The recent Swedish results were announced by Professor Bo Oberg, a virologist at Sweden's Karolinska Institute. FLT is being developed by the Medivir research company, which wants to sell the patent rights to a large pharmaceutical company, probably one in the United States. Dr. Oberg previously headed an AIDS research team at Astra, the Swedish pharmaceutical company which also developed foscarnet, an anti-HIV treatment now also being used for CMV retinitis. The team screened almost 2,000 chemicals for anti-HIV activity.

FLT causes bone-marrow suppression like AZT, but it appears to have much less toxicity at an effective dose.

Dr. Oberg was quoted as saying that two years of laboratory and human testing would be required before the drug could be marketed. We suspect that this time-frame reflects the fact that FLT will probably be developed in the United States (Sweden does not have enough AIDS/HIV patients to run trials). In the past, Astra has had major problems trying to conduct AIDS research in the US; see Wall Street Journal editorial of April 21, 1987 concerning Astra's frustration and withdrawal from US trials of foscarnet two years ago.

Many people would be willing to take the risk of trying FLT now, with doses based on what worked in monkeys and on human toxicity data from the earlier cancer studies. We could know in weeks or months whether or not this drug could make a substantial contribution to AIDS treatment. Red tape alone - or rather the empires and vested interests which benefit from it - will extend that time to years, unless the public insists that AIDS be treated as an emergency instead of business as usual.

* Azidouridine (AzdU). Formerly called CS-87, azidouridine showed no toxicity when given orally to animals in high doses. In laboratory tests, it is effective against HIV in macrophages as well as in blood cells.

The first human trial is planned for early 1989.

For more information, see the AmFAR directory.

* D4T. Animal and laboratory studies have found this nucleoside analog considerably less toxic than AZT, and about as effective in stopping HIV. Human trials are planned for early 1989. For more information, see the AmFAR directory.

* CD4. Despite the publicity about CD4, we put it last in this list of best treatments because so far we have not heard much enthusiasm from those with direct experience with the drug. However, the current trials were not designed to test for efficacy, and they started with very small doses. CD4 may prove effective in further testing.

HIV QUALITY OF CARE

ACTION NOW, an ACT-UP affiliate in Orlando, Florida is compiling a file of stories sent to them by anyone who feels they received inferior medical care for HIV. If you have had such an experience, mail it to ACTION NOW, attn: Madame de Farge, 4618 Canna Dr., Orlando, FL 32809. The results of the survey will be published.

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If you are interested in subscribing to ALERT, please send your name and address to: ALERT, c/o UFMCC AIDS Ministry, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029.